

doi:10.1038/nindia.2013.2; Published online 17 January 2013

Interview

Research that lights up lives

Pawan Sinha, whose work among visually impaired children in India received a U. S. Presidential award in 2012, talks to Vijaysree Venkataraman about a mission that seamlessly blends research with a humanitarian cause. Sinha is from the Department of Brain and Cognitive Sciences at the Massachusetts Institute of Technology.

Q. What does your work entail?

A. Most research benefits society long after it's over. However, in some instances, the research process directly benefits people's lives. Fortunately, we have been part of one such process: we call it Project Prakash. It grew from the confluence of a humanitarian mission and a fundamental scientific quest. The mission is to bring light into the lives of curably blind children and, in so doing, answer some fundamental scientific questions about how the brain develops and learns to see.

Q. You are based in Boston. But the work is in India, correct?

A. India is home to one of the world's largest populations of blind children. Nearly 400,000 children in the country are either blind or severely visually impaired. The visual handicap, coupled with extreme poverty greatly compromises the children's quality of life; childhood mortality rates are greatly elevated and prospects for education are severely diminished. Project Prakash seeks to identify and treat blind children, and simultaneously, build awareness amidst the rural populace regarding treatable and preventable blindness.

It also provides us an opportunity to study one of the deepest scientific questions: How does the brain learn to extract meaning from sensory information? The researchers have begun following the development of visual skills in these unique children to gain insights into fundamental questions regarding object learning and brain plasticity. This is a unique window into some fundamental mysteries of how the brain learns to extract meaning from the world. The humanitarian initiatives are creating a population of children across a wide age-range setting out to learn how to see.

Q. How do you find children who are candidates for treatment?

A. Outreach is perhaps the most logistically complex and challenging aspect of Project Prakash. We have provided surgical treatments to 448 children, and non-surgical care to 1400. To identify these children, we had to screen over 40,000 children in many states of India.

We realized early on that we simply couldn't expect children needing treatment to show up on their own at the hospital in New Delhi. Many of them and their parents do not even know that their conditions are treatable. The parents often ascribe their child's blindness to bad karma – inviolable cosmic justice for bad deeds in a previous life. Faced with these preconceptions, we understood that we had to be proactive. We would need to go out into



Pawan Sinha with a child treated for congenital blindness.

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the villages to find children who were curably blind.

So we organize ophthalmic screening sessions in villages and small towns. A few weeks before our team's visit, we send word to villages about the 'eye camp' and encourage them to bring all children with visual problems for a free check-up. On the day of the session, a team of primary health-care workers and optometrists sets up a simple screening station in the village and does eye check-ups of tens, sometimes hundreds, of children. These sessions allow us to identify curably blind children and also those whom we can help non-surgically (such as children with eye infections than can be dangerous if left untreated, or those with uncorrected refractive errors). The candidates for surgery come to New Delhi for a more thorough ophthalmic examination and, if there are no counter-indications, then the child is given a date for surgery.

All expenses of surgery and transport are borne by Project Prakash.

Q. What are some scientific insights you have gathered thus far?

A. One of the potentially far-reaching results is evidence of recovery even after prolonged congenital blindness. These findings argue for a reconsideration of some long held conceptions regarding brain plasticity and time-lines of learning.

Having followed the post-operative development of several children, my students and I have found that while some aspects of vision, such as acuity, are compromised by a history of deprivation, there is evidence of skill acquisition on a variety of functional vision tasks ranging from simple shape matching to object and face recognition.

The human brain, these findings suggest, retains an ability to launch programmes of visual learning well after the normal period of their deployment has passed. These results have significance for basic neuroscience as well as the practice of paediatric ophthalmology and the implementation of late stage blindness treatment programmes.

Q. What lies ahead for Project Prakash?

A. Sociological aspects of the work guide the evolution of the project. I would never have, for instance, expected that parents might actually prefer to have their child remain blind just so that they can stay enrolled in a school for the blind that gives them free food and clothes. Yet, the level of poverty in some households is so extreme that this happens.

Another surprise for us has been the difficulty Project Prakash children have encountered in entering the educational mainstream despite having sight. But, their age (too old to be enrolled in grade 1) often keeps them from starting their educational journey. This is indeed a tragedy and one that we are working towards addressing. Moving forward, we want to add an educational component to the medical and scientific missions of Project Prakash. We intend to do so by providing a 'compressed' educational course to the children to bring them up to an age-appropriate level so that they can then enter the regular educational stream.

The challenge that we have to meet in the coming years is to accomplish a seamless integration between medicine, research and education, at a scale many times that of our current operations. A good way forward is to set up an integrated campus with a pediatric hospital, a school and a research facility.

The key need to realize this dream is funding. Our estimate for the center is \$20 million. This seems like a daunting figure, but considering the multifaceted impact it can have on thousands of children, it is a small sum.

Nature India EISSN 1755-3180

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